

Primary Support Persons for Individuals Who Are Visually Impaired: Who They Are and the Support They Provide

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As the proportion of older adults in the U.S. population grows, the prevalence of visual impairment related to cataracts, glaucoma, macular degeneration, and diabetic retinopathy will increase as well. According to Friedman, Congdon, Kempen, and Tielsch (2002), "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades." Individuals who are visually impaired require various degrees of support and assistance in their daily activities. This assistance is frequently provided by a "primary support person," who may be a family member or friend who assists with all day-to-day activities. Despite research on the experiences of primary support persons for individuals with other types of chronic conditions, such as dementia, stroke, and cancer, there has been little research on the individuals who provide primary support to persons who are visually impaired. It is not clear whether these care givers feel a sense of strain or feel burdened by their role. As Chia et al. (2004, p. 73) noted, "the burden [of caring for persons with] visual impairment will increase as [the] prevalence [of visual impairment] increases ... due to the aging population." The study reported here sought to provide some preliminary data on the experiences of primary support persons of individuals who are visually impaired.

BACKGROUND AND SIGNIFICANCE

Research related to the experience of visual impairment has

focused mainly on the perspectives of individuals who are visually impaired. McIlvane and Reinhardt (2001) found that high-quality support from family members and friends was associated with lower levels of depressive symptoms among 241 elderly patients of a vision rehabilitation services agency. In addition, it was the quality of the social relationships, not the quantity of social network members, that was most important for the functioning and well-being of these older adults. Adaptation to visual impairment was better in the older adults who reported receiving high-quality support. However, McIlvane and Reinhardt did not measure the type or amount of support activities that these elder adults received. Without this information to describe the context and extent of the needed support, it is difficult to generalize the findings to other populations and situations.

Bernbaum, Albert, Duckro, and Merkel (1993) found that diabetes-related visual impairment was a major stressor in marital relationships. They noted that "regardless of the length of the pre-existing relationship, the greatest risk to the marriage occurs soon after the visual impairment" (p. 676). In their sample, of the couples who were in a committed relationship at the time of the onset of one partner's visual impairment, 50% were later separated; the mean amount of time from the onset of the visual impairment to separation was 1.6 years. Although both health and vision professionals must address this potential stress to help families cope with visual impairment, research has provided insufficient data and recommendations for such interventions.

The research questions for this study were as follows: (1) What are the demographic and social characteristics of primary support persons of individuals who are visually impaired? (2) What support activities are provided by the primary support persons, and how much time per week is spent doing these activities? and (3) How do these primary support persons score on the Caregiver Reaction Assessment (CRA), an instrument that was designed to measure caregivers' burden or strain? (Given et al., 1992).

METHOD

Sample

A purposive, consecutive sample of 28 adults who reported being the primary support persons for individuals who were visually impaired was recruited for the study through a low vision services clinic. The visually impaired individuals had other chronic health problems; however, their primary support persons were recruited if visual impairment was reported to be the most disabling or burdensome condition requiring support. Criteria for inclusion in the study were being at least 18 years old, a family member or friend of a visually impaired person with an acuity of greater than 20/40 and markedly reduced visual fields of greater than 20/70, self-identified as the primary support person of a visually impaired person, and willing to complete the survey (a total of 55 survey packets were distributed; 28 were returned).

Procedures

The research followed the tenets of the Declaration of Helsinki and was approved by the Institutional Review Board of the University of Colorado at Colorado Springs. A low vision specialist identified potential participants, and each potential participant was offered a description of the study and, if interested, the survey packet. A cover letter further described the study. Those who wanted to participate completed the questionnaires and mailed them to the principal investigator in prepaid, preaddressed envelopes. A statement in the cover letter stated that completion and return of the surveys implied informed consent to participate in the study. The survey packet included a demographic form, a log of support activities provided during a one-week period, and the CRA instrument. The response rate from all the primary support persons who accepted the survey packets was 51%. Data was entered and analyzed using SPSS 13.0.

Instruments

The demographic data included the participants' age, gender, relationship to the individual who was visually impaired, employment status, months or years as a primary support person, the total amount of time (in hours per week) spent providing support, whether the primary support person lived with the visually impaired person, a self-assessment of health status, and the visual acuity of the person who was visually impaired (provided by the low vision specialist). The participants also kept a log in which they listed the support activities and amount of time spent per week in providing support.

CRA is an instrument with well-documented validity and reliability in various populations (Given et al., 1992). Twenty-four items are scored on a 5-point Likert scale (from 1 = strongly disagree to 5 = strongly agree). Several items were reverse scored. Higher scores indicate more burden or strain, and mean scores higher than 2 on a 5-point scale suggest burden (B. A. Given, personal communication, January 5, 2006). Five subscales of the CRA measure the impact of the experience on various dimensions of burden: schedule (5 items), family support (5 items), health (4 items), and finance (3 items). Self-esteem in association with care activities (7 items) was also measured. Previously published internal consistency measurements (alpha coefficients) for the subscales are schedule (0.82), esteem (0.90), family support (0.85), health (0.80), and finance (0.81) (Family Care Research Program, 2004). Mean scores and internal consistency measures for each subscale were calculated for this sample.

RESULTS

Of the 28 participants, who ranged in age from 36 to 88 years old (mean = 61), 57% were female. Their relationship to the persons who were visually impaired person varied; 9 were wives, 8 were husbands, 6 were daughters, 3 were sons, 1 was a mother-in-law, and 1 was a friend. Eleven participants were employed full-time, and 4 were employed part-time in addition to their support role; 9

were retired; and 4 were not employed. Of the 28 participants, 15 said their health was "good," 7 said their health was "excellent," 5 said their health was "fair," and 1 reported "poor" health. The mean amount of time that the participants had served as primary support persons was 86 months, or about 7 years (median = 48 months, range = 1-360 months). The mean acuity level of the individuals with visual impairments was 20/240 (median 20/100).

The types of support activities reported by the participants varied (see [Table 1](#)). Transportation (to medical appointments or for leisure activities) was the most frequently listed support activity, followed by shopping, which included putting away groceries at home. The third most frequently cited support activity, administrative tasks, included check writing and balancing checkbooks, letter writing, mail sorting, and filing. Mealtime preparation, the fourth most frequently cited support activity, included food preparation, cooking, and cleanup. The amount of time spent performing support activities is summarized in [Table 2](#).

Walking ranked as the highest support activity in terms of time, but only one participant specified the amount of time spent in this activity and, therefore, this is not a representative figure.

Recreation, cited by four participants, ranked as the second-highest activity related to time and included leisurely drives, special family occasions, and outings for dining or pleasure. Mealtime preparation was the third- highest time-intensive support activity, with an average of more than 7 hours per week spent in this activity. It was followed by personal care activities, which included hygiene and nail and hair care and averaged about 5 hours per week. Transportation, which was the most frequently listed support activity overall, ranked fifth in terms of the amount of time spent, with about 5 hours per week dedicated to this task. Two participants listed activities but did not specify the amount of time spent in these activities.

The scores on the CRA indicated that, as an aggregate, the

participants were feeling mild burden or strain in their role; however, they also had a fairly high level of self-esteem in their role. [Table 3](#) shows the mean scores and internal consistency measures for each subscale.

DISCUSSION

Transportation has been previously cited as one of the most common support needs of persons who are visually impaired. In a study of the needs of visually impaired individuals in Canada, 10% cited transportation as a barrier to employment, and 12% cited transportation as a needed service that they were not receiving (Gold & Simson, 2005). In another study, rehabilitation providers identified transportation as one of the pervasive barriers to obtaining employment for persons with visual impairments (Crudden, Sansing, & Butler, 2005). Similarly, transportation was the most frequently mentioned issue by visually impaired teachers of students with visual impairments in meeting the demands of their role (Lewis, Corn, Erin, & Holbrook, 2003). Knowledge of the types of primary support needed by people who are visually impaired and the impact of providing support by family members and friends is useful for the coordination of adequate services by local and state governmental agencies. Low vision optometric and ophthalmologic providers can work more closely with certified vision rehabilitation teachers to coordinate support services offered in the community, matching the needs of the individual who is visually impaired with the specific services that the person needs.

For this sample of primary support persons, the results of the CRA analysis suggest that they felt mildly burdened in their role. The types of support needed by individuals who are visually impaired tend to require less constant, hands-on personal care (such as bathing and toileting) and more intermittent, instrumental support (like providing transportation, managing finances, and preparing food). However, the amount of time required to support instrumental activities may actually be greater

than the time required to provide hands-on personal care. This is an area that needs further study.

This study was limited by the small convenience sample. The primary support persons who accepted survey packets but did not return the surveys may have been different in some way from those who chose to return the surveys. In addition, the completion of three questionnaires may have been overwhelming.

The need for additional study of the impact of visual impairment on individuals, families, and society will continue to grow. Small studies, such as the one reported here, have been conducted to evaluate social support provided by family members and friends (Travis et al., 2003), depression among Latinos who are visually impaired (Paz, Globe, Wu, Azen, & Varma, 2003), and the impact of visual impairment on individuals' quality of life (Vu, Keeffe, McCarty, & Taylor, 2005). Additional funding and large studies are needed to design and test interventions that are aimed at serving individuals who are visually impaired and their primary support persons.

In summary, the main support activities provided by the primary support persons included instrumental support, such as transportation, help with administrative tasks, and shopping and meal preparation, and the participants' CRA scores revealed that they felt mild levels of burden in their role. Further study is needed with the primary support persons of individuals who are visually impaired to focus assessments and interventions appropriately and to assist policy makers in making informed public policy decisions regarding transportation and other community services that are available for individuals who are visually impaired.

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